Frequently Asked Questions Concerning Creutzfeldt-Jakob Disease (CJD)

Where is testing being done to confirm the diagnosis of CJD in the possible cases in Idaho? When will you let us know what the results are?

Brain tissue, usually obtained at autopsy, is required to confirm the diagnosis of a prion disease. An autopsy is only performed when the patient or patient's family agrees to have one done. After autopsy, brain tissue is sent for testing to the National Prion Disease Pathology Surveillance Center (NPDPSC) in Ohio. For more information about the NPDPSC and the tests the center can do, visit their website at http://www.cjdsurveillance.com/. An updated results summary will be released on the main CJD page as new results become available, but only after family members have been informed. Testing and a final report may take two months or more to complete after the NPDPSC has received the brain tissue.

Why won't you release information about individual cases?

To protect the privacy of individuals and families, IDHW and local public health districts will not release information that could lead to the identification of individual patients.

Why isn't the Centers for Disease Control and Prevention (CDC) here to investigate?

CDC experts are actively assisting in the investigation through frequent consultations. A CDC neuroepidemiologist visited Idaho to lecture on CJD at continuing medical education seminars and to further evaluate records on non-autopsied cases. Local and state health departments are responsible for conducting health investigations among their state's residents. States may choose to invite the CDC to come to Idaho to further assist in an investigation if additional resources are needed.

What else are IDHW epidemiologists doing about CJD?

IDHW epidemiologists will continue to monitor for new cases. To find possible cases and to help obtain the autopsies needed for diagnosis, IDHW sent a letter to all neurologists, pathologists, and other physicians who may see CJD cases in Idaho. The letter informs them of the need for immediate reporting of suspected cases to the public health department, the importance of autopsy, and how to contact the National Prion Disease Pathology Surveillance Center.

In 2006, IDHW plans to participate in providing education to embalmers, morticians, and funeral home directors about handling persons suspected of having CJD.

Why is CJD being investigated and not other diseases?

Investigations into several other disease concerns in Idaho are ongoing. Recent media attention has focused on this particular investigation because it is a new investigation and there is heightened public concern about this disease.

Why was CJD made reportable?

Some states, including Idaho, made CJD and other prion diseases reportable recently to help monitor for variant CJD after Bovine Spongiform Encephalopathy (BSE, or "Mad Cow Disease") was detected in a cow in Washington State in December 2003. (See http://www.cdc.gov/ncidod/dvrd/bse/ for more information on BSE in the United States.

I want to report my relative's case of CJD to be sure it is investigated. Whom should I call?

If your relative is a resident of Idaho, ask the attending physician if the case has been reported to the health department in Idaho. In Idaho, physicians must report suspected or confirmed cases of CJD and other transmissible spongiform encephalopathies (prion diseases) to the health department.

If your relative is a resident of another state, contact the local or state health department in that state to find out if physicians are required to report CJD in that state. Not all states require physicians to report cases of CJD or other prion diseases. Links to your state health department can be found at http://www.cdc.gov/mmwr/international/relres.html.

Where can I get more information about CJD?

See the following links for information about CJD.
Centers for Disease Control and Prevention
http://www.cdc.gov/ncidod/dvrd/cjd/

National Library of Medicine and National Institutes of Health
http://www.nlm.nih.gov/medlineplus/ency/article/000788.htm
http://ghr.nlm.nih.gov/condition=priondisease

National Institute for Allergy and Infectious Disease
http://www.niaid.nih.gov/publications/prion.htm

The National Creutzfeldt-Jakob Disease Surveillance Unit (UK)
http://www.cjd.ed.ac.uk/intro.htm

World Health Organization
http://www.who.int/zoonoses/diseases/prion_diseases/en/

Medscape article on prion diseases (must register to view)
http://www.medscape.com/viewarticle/410863

Are there any support groups for families of CJD patients?

Yes. A listing of support groups can be found at
http://www.rarediseases.org/search/rdbdetail_abstract.html?disname=Creutzfeldt+Jakob+Disease

I'm learning that personal and family medical histories help physicians diagnose and treat their patients. What can I do to make sure that my doctor has my complete medical history?

You can develop your personal medical history and update it whenever there is a change. You can also create a medical family tree. The following links provide information on how to create your own health record and how to make a medical family tree.

E-medicine Consumer Health
Family medical records
http://www.emedicinehealth.com/articles/11909-1.asp

American Association of Family Practitioners
Creating a Health Journal
http://www.familydoctor.org/838.xml

The Mayo Clinic
How to compile your family medical history
http://www.mayoclinic.com/invoke.cfm?id=HQ01707